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ABSTRACT

Acquired Immune Deficiency Syndrome (AIDS) has become an increasing problem throughout the nation. Experts predict that there will have been 270,000 cases, including 179,000 deaths, by 1991. The disease has devastating psychosocial as well as physical effects. Neither preventive medicine nor a cure is anywhere in sight. Everyone needs to be educated about AIDS to be able to separate fact from myth and rumor. Massive education campaigns in gay communities correlate with significant drops in the rate of homosexual infection. Conversely, intravenous drug users have not been educated and are still considered the prime carriers of AIDS into the hetereosexual world. Laws are needed to prevent discrimination against people with AIDS. As the costs of treating AIDS increase, much of the money will have to come from the government. Less money will then be available for education and social services. While AIDS alters the life of the patient, the caregiver's life also changes. Much is being done to develop vaccines, develop prophylactic and therapeutic drugs, modify the environment, and modify behavior for the prevention of AIDS. AIDS continues to have an enormous impact on educational practices, health care, business, and social institutions. (YLB)

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Victims of AIDS:

by
Doris F. Peyton

Presented at

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Spring 1988

Victims of AIDS: Family, Society, Cost and Outlook.

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AIDS has become an increasing problem throughout our nation. By 1991 experts predict there will have been 270,000 AIDS cases including 179,000 deaths. There are an estimated 1 to 1.5 million AIDS carriers in the United States. As of February 1988, 53,814 cases had been reported to the federal Centers for Disease Control (CDC). Out of these 65 percent were homosexual or bisexual males 17 percent were heterosexual intravenous drug abusers sharing needles and 8 percent are IV drug abusers who are also homosexual or bisexual. Two percent received tainted transfusions; 1 percent are hemophiliacs. Only 4 percent of cases occur in hetersexuals who claim not to be drug users. Three percent are undetermined.

AIDS (acquired immune deficiency syndrome) was first diagnosed in the United States in 1981, after a small number of homosexual men in San Francisco and New York were found to have the previously rare form of pneumonia known as pneumocystis. Carinii pneumonia (PCP) or kaposis sarcoma (KS) a rare kind of cancer. It shows up as purplish - black lesions on the skin. It became known as the gay plague since it was originally limited to homosexuals and was not believed to be a threat to the mainstream of heterosexual society. The feeling of many was that people within this group deserved their illness.

The origin of AIDS is believed by most to have come from the Old World Monkeys in Africa. Other theories about the genesis of AIDS is that it is a cousin of syphilis, a sex-

ually transmitted disease. Another theory is that it was first transmitted by injections of gamma gloubulin, a blood product often used to prevent hepatitis. In the mid- 1970's this was very commonly used in many homosexuals with hepatitis.

Half the gay men in San Francisco and New York are said to be infected with the virus. In the future the spread of AIDS is not only going to be in the big cities but also the small towns and rural areas of this country.

*26 year old, Steve Forrest, a native of Williamson, WV, a coal town in the Appalachian Mountains is a prime example of how an AIDS victim is treated in a small town. He is, a homosexual, a fact he did not reveal to his family until after graduating from high school. This soon became public knowledge and many would not accept this. He was treated as an outcast.

In 1981 he went to Dallas, Texas and lived in a gay community in his own apartment which he shared with his lover. At last he did not feel like an outsider. He worked there and was happy until he became ill with AIDS. He and his lover split up.

Steve knew that the continual bouts of shingles, diarrhea, thrush and bronchitis meant only one thing. He could not face it. Instead, he spent entire days in bed, sometimes not even knowing what day it was. When he was not sleeping, he was drunk or stoned. By day, thoughts of suicide possessed him. By night, he had terrifying nightmares about being buried alive.

*Name changed at request of family.

Eventually he decided that if he was going to die he would like to be with his loved ones and friends back home in Williamson. He learned quickly that it was no haven for an AIDS victim.

Except for Steve's father and sisters, almost none of his relatives or old friends would associate with him. Even police and church going people did not feel safe in his presence.

On one hot summer day he went with his sister, Liz and her family to swim in the town pool. The mayor immediatly ordered the pool to be closed down on the pretext of equiptment problems due to numerous complaints of the townspeople. The pool was evacuated and scrubbed down and before it reopened 12 to 16 times the usual amount of chloring was dumped into the pool.

The U.S. Surgeon General, Dr. Koop's report plainly tells us that AIDS cannot be spread from "casual, social contact"[1] or swimming pools.

The story came out on the front page of the local newspaper. After that, every major newspaper and TV station in the state as well as the national press carried the story.

The townspeople spread rumors he was licking fruit in a local supermarket and spitting in Wendy's salad bar. Some felt that since he knew he was going to die he might be trying to take others with him. Many merchants' businesses dwindled due to the false rumors.

He was soon made a prisioner in his own sister's house. In public he was ridiculed and people fled from him. Vandals even shot the windows out of his car.

Finally he fled, leaving behind him what happens in a small town with an AIDS victim there.

He is now living in Charleston, WV, a town where he best of all is not known, helping as a volunteer worker in a state-wide AIDS education project. Here he receives housing, medical and emctional support.

He seldom goes back to the Williamson area. When he does it is by night for fear someone who recognizes him may shoot him or torch his father's home.

There is no question that AIDS has spawned many frightened people, and frightened people do not always behave rationally.

Long after Steve's departure Liz says her inlaws have ceased to visit and old friends turn away on the street.

While his sister, Karen gets called into the principal's office for fighting with schoolmates who have made fun of her brother, she plans to move away from it all after she graduates next June.

Steve's father is bitter, too. There are going to be more AIDS cases in the Valley, he says, and "some of these people who have been so harsh and cruel and unthinking will have to think, because it will be their children."[2]

The psychosocial effect of AIDS can be as devastating as the physical effects. When AIDS strikes it brings about various reactions from friends, family, lover, health care giver and the infected one also. The victim is often wracked with quilt, anger and uncertainty. Often they are treated like lepers, and face a lonely battle against illness and prejudice.

No preventive medicine except prudence is anywhere in sight and neither is a cure. No one knows for sure but even the most optimistic researchers do not foresee such breakthroughs until at least late in this century. The development of an AIDS vaccine has proved far more difficult than initally imagined.

Scientists are working on finding drugs that will alleviate symptoms and slow the virus's destructiveness. So far the Food and Drug Administration has approved only one such drug, Azidothymidine, known as AZT. It has prolonged the lives of some patients, but the side effects are serious and is far from a cure.

AIDS patients do not die of AIDS; they die of strange, intractable diseases that invade and destroy the body after the AIDS virus has ravaged its immune system.

Studies show that men with AIDS outlive women by six months or more. Women also become sicker, suffering several simultaneous infections. While men usually have one at a time.

World health authorities believe that AIDS will soon be the leading cause of disease - related death. Most people who are infected look and feel fine. An estimated 90 percent or more do not suspect they are carrying the virus. The virus can be transmitted to anyone they have sex with or by sharing needles, since it is contracted through blood or semen.

A few states require the AIDS antibody test for all couples when applying for a marriage license. Similar bills are being followed in other states.

The only way to protect the one they love is to have the AIDS antibody test before marriage unless they know the AIDS antibody status of all of his or her sex partners for the last ten years. Secondly if either have had a blood transfusion after 1977 and thirdly if intravenous drug users have shared needles, testing needs to be done.

A 50 year old woman donated a unit of her own blood to herself before she was to have a routine hysterectomy, only to discover her blood tested positive for the AIDS virus. The woman had no symptoms, but had a recent sexual relationship with a man who did not know he was carrying the virus.

All women are strongly advised not to become pregnant it they or their partners are in a high risk group or know either of them are AIDS antibody positive. The risk of infection to the baby is very high.

Pediatric AIDS is not a pleasant sight. They are miserable during the entire course of their fulminant, always fatal disease. Often the mother, herself will have a terminal illness, leaving the baby parentless.

In Indiana recently, an unsuspecting girl married a graduate engineer, never realizing that he had experimented briefly with needle drugs in his undergraduate days. She never suspected he was an AIDS carrier. Upon becoming pregnant, she soon became very ill and died. Her baby died also.

Through fear of the unknown and ignorance of how AIDS is spread in Arcadia, Florida last year the three young Ray brothers and their family were forced to find a town that

would allow the children to attend school. They are hemophiliacs and due to this condition have received contaminated blood products, through which they picked up the AIDS virus. In addition, their home was burned to the ground and it was suspected to be Arson.

Experts duleate the threat to heterosexuals. So far, AIDS cases are rare outside the known risk groups. Some researchers say that's a sign for hope; others say it is a sign of luck. Surgeon General Dr. C. Everett Koop criticized articles minimizing the risk of heterosexual transmission of the fatal disease. While only 4 percent of current AIDS cases are reported among heterosexuals that proportion is expected to rise to 5 percent in the 1990's. Many heterosexuals are terrified of contracting it.

AIDS is already affecting the way people think about sex and relationships. For the single women the romantic evening is not what it used to be thanks to the spector of AIDS. Many have called sexual retreats, while others have become more selective about their partners. Some require their partner to have the AIDS antibody test before having sex.

People in all walks of life need to be educated as much as possible about AIDS to be able to separate fact from myth and rumor. Many books and articles are being printed with misinformation about the disease.

Massive education campaigns have been provided since 1982 in gay communities and the rate of homosexual infection dropped significantly. On the other hand intravenous drug users have not become so educated and are still considered

the prime carriers of AIDS into the heterosexual world.

A well known writer Randy Shilts, believes there is a level of infection in the Bronx that approaches that in Central Africa with the rapid spread of AIDS among intravenous users and their sex partners.

In the future, countries with few AIDS cases, such as China and Russia may refuse entry to high - risk foreigners.

There is much controversy whether testing for the HIV (human immunodeficiency virus) should be mandatory or voluntary. The purpose in giving the test is to promote a behavioral change. Homosexual men have responded well to knowledge about AIDS safety; but not so in all groups. The experience of some health educators has confirmed AIDS carriers often behave in riskier ways than they did before they tested positive for the AIDS antibody. This is especially true of intravenous drug abusers.

Infection with HIV does not necessarily mean you will get AIDS. About one third of those infected are expected to get the disease within 7 years, according to the CDC in Atlanta. Another third will get AIDS related complex (ARC), which may lead to full blown AIDS eventually. The last third may have no symptoms and never get the disease but still be carriers of the disease. No one knows for sure what the incubation period is.

Laws are needed to prevent discrimination against people with AIDS. People able to work should be allowed to keep their jobs, get an education and be free to live where they please.

A medical student at a major southeastern university infected with the AIDS virus was kicked out of school on her first day. A professor asked her to leave.

She contracted the virus in a hospital where she worked by leaning into a syringe containing blood of an AIDS patient.

The student was reenrolled after hiring an attorney, threatening suit, and getting support of doctors from the hospital where she worked.

The other medical students were reportedly informed if they involved themselves in the controversy they could jeopardize their finishing school.

The faculty members violated the student's privacy by letting it be known she had tested positive for the AIDS antibody and the other students were not treated fairly by the threat they might not finish their school by becoming involved in the situation.

By 1991 the cost of treating AIDS patients is expected to be between $8 billion and $16 billion a year. $500 of each taxpayer's bill may go to AIDS care. It may eat up as much as 13 percent of medicaid.

Society as a whole is picking up much of the tab. Some money will come from private donations. Millionaire Malcom Forbes recently made a gift of $1 million to the American Foundation for AIDS Research, while a gala benefit, amidst the glitter and glamour of Elizabeth Taylor and a parade of other celebraties, raised $2 million for AIDS.

Much of the money will have to come from the government.

Today's young people will not have as much money available to them for education, social services, et cetera as the previous generation did, because a lot of money will go to AIDS research and care.

Up to now insurance companies have paid for much of the cost of an individual's treatment and care. Some of these people may have insurance through a company where they are employed. They may possibly exceed the limits of their insurance or leave their jobs due to disability. Wherein being unable to get other insurance, since AIDS is a preexisting condition they must come up with the money themselves. If they do not have it they must rely on medicaid or welfare. Ultimately all of society will pay the price in higher insurance premiums, higher taxes, or reduced services in other areas.

Life insurance companies may go bankrupt from the many thousands of victims dying long before their time.

a prominent futurist and banker Hank E. Koehn shares his experiences with AIDS and how the disease changed his view of life and his understanding of himself.

His doctor had advised him to have the AIDS antibody test but at first he rejected. Apparently he was like many others, avoiding the information that he already suspected. Finally his doctor convinced him he could treat him in a more knowledgeable way if he knew the results of the test.

On February 20, 1987 his world came to an end while waiting on a flight to Los Angeles in an air terminal in San

Jose, California when by telephone his doctor informed him the test was positive.

Upon keeping an appointment with his doctor the next week he mentioned having difficulty using his left hand. The doctor ordered a brain scan for the next day to check out his theory that the difficulty with the hand might be due to brain damage as a result of the now active AIDS virus.

The results showed a lesion on the right side of the brain. The doctor unwittingly transmitted the subconscious emotional message that he had a terminal condition.

Arrangements were made for him to enter the hospital for a complete diagnosis. Koehn delayed going until he turned over his client commitments to an associate, and visited an attorney to arrange matters in the event he never left the hospital.

The hospital stay was not unpleasant, even though he had not been in one for over fifty years.

The doctor indicated the brain lesion was due to toxoplasmosis infection. This protozoan is usually present in all of us, but our immune system keep it in check. The infection in his brain was slowly taking away his ability to use his left hand and arm.

Koehn had his first seizure on the day he was to leave the hospital. Utterly terrified he was told this could become a common event and was put on Dilantin.

The doctors were surprised at his acceptance of his limited prospects, declaring he had led a full, happy, productive and successful life. He did not feel cheated and could therefore

face his impending death calmly.

He felt he would most likely not live beyond the end of the year and when it was time to die he would simply go to bed and stay there. His calmness was a result of an accepted certainty.

He decided also, not to work any longer for fear he would have a seizure while giving a lecture, or he felt he would be rejected when word got out about his having AIDS and that his clients would be appalled by his choice of lifestyle.

Upon leaving work he soon found out he had lost his sense of self - worth and without his work soon lost interest in the outside world.

His days and nights were filled with emptiness having no interest in doing anything, although he was well cared for in a comfortable home, taking his medication on schedule and sleeping at intervals.

While attempting to make a few out of town trips the activity led to emotional dis aster by having a seizure on the plane and, once, while going through security. All this made a continued resignation to dying very easy.

After talking to a friend he came to the conclusion he had given up too quickly. He had been receiving some counseling to stablize his emotional state which he felt he had under control without help.

To his surprise he found his inner needs were spiritual or metaphysical. On talking to more friends he found that during illness they had reached the same conclusions in their own lives. However, on suggestion of friends he read several

books including one written by Louise L. Hay.

Miss Hay, a metaphysical healer, had been working with both cancer and AIDS patients successfully. She had become a legend in the gay community. After listening to several of her tapes over and over his attitude began to change from resignation to a belief that he could play a major role in healing himself.

He could not understand the reason, but he had an overwhelming urge to see the ocean.

Upon arriving at the ocean as he sat in a lounge chair looking at the waves he realized why he had wanted to come. The pattern of the waves placed him in a relaxed state. His mind began to float as he recalled a long - forgotten feeling from early life, when he was an only child without parents. He had felt abandoned, and his feeling would be repeated in his teen years and in two adult relationships.

Koehn had not realized he feared abandonment, but with his overpowering fear, now as a grown man with AIDS, this was again what he feared.

Slowly he began to realize that no matter now uncertain his life seemed, there could be a future. And he could exercise some control over his existence. He began to reach out to others and to his amazement, many of his friends accepted is line of thinking concerning the healing process.

He placed himself on a religious retreat in his own home as he began his spiritual search for a meaningful identity. He had become a far different person than what he was when he was diagnosed with AIDS.

For the first time in his life he cried easily. His crying was not a result of fear as much as an emotional expression or outlet for pent - up anger and frustration.

Frequently being overpowered by a feeling of being all alone in a strange, dark place, and crying he developed an almost desperate need to be hugged and held closely as he did when he was a child.

He had always been an independent person and he was being transformed into a helpless being who needed help with everything he did. The massive change in so short a time left him unprepared to understand or to control himself.

AIDS is perceived to alter the life of one person, the patient, but the debilating condition of the patient needed constant help, the care giver's life changes also. The disease dominates every discussion and action.

Accepting care and understanding limitations are skills one must learn. Expectations must be adjusted to a new reality.

To Hank E. Koehn learning to reach out to others and accept love was a great challenge. He could now empathize with terminally ill cancer victims and the helpless feelings if the elderly as they are forced to depend on others for their existence.

Unfortunately, the AIDS patient is also today's leper. The attitudes of many are similar to those focused on leprosy victims.

Hank E. Koehn died of AIDS on September 29, 1987. He was a frequent speaker at banking and other groups over the years. Koehn said he revealed he had AIDS and wrote about his illness

in the hope of helping to educate the business Community about AIDS. His concern was that banks may be hiding their heads in the sand, believing they employ no homosexuals or bisexuals and that none of their people will come down with AIDS. He maintained that their employees, their workers' families, their friends, and their customers are potential victims. This makes it imperative for businesses to be knowledgeable, so that policies and procedures can be put in place to deal with an emerging problem that will infringe on their operations.

The growing impact of AIDS will present us with more challenges and get to the heart of what kind of people we are throughout the rest of this century. It will affect all directly or indirectly.

Since there is no cure for AIDS and a vaccine is not likely to be found in this century, literally hundreds of thousands of people will die from the fatal disease the world over.

There is much being done to develop vaccines, develop prophylactic and therapeutic drugs, modify the environment, and modify the behavior for the prevention of AIDS.

The change in our society will affect educational practices, health care, business and social institutions.

Monogamy and marriage may become idolized as people search for one lifelong love. Divorces may decline.

It is the deadliest disease of our time and no other epidemic has brought about as much fear. AIDS, perhaps because it always kills, has fired emotions that extend far

beyond its victims, touching the lives of the uninfected and uninvolved in ways they cannot anticipate.

FOOTNOTES

[1]Rosellini, Lynn and Erica E. Goode." AIDS When Fear Takes Charge." U.S. News & World Report, U.S. News & World Report, Inc.. 12 Oct. 1987, p.69.

[2]_____, p. 70.

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